



Human
Genetics
Commission

Human Genetics Commission

**Fifth Report from
April 2005 to March 2006**

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Chair's introduction

I am delighted to present the fifth annual report from the Human Genetics Commission and reflect on what has proved to be a very busy year. The Commission has continued to make important and timely contributions to the wide arena of developments in human genetics and how these developments impact on individual lives.

It has been three years since the Government published its White Paper on Genetics "*Our inheritance, our future: realising the potential of genetics in the NHS*", which set out the challenges and opportunities presented by the advances in human genetics. This was matched by a wide-ranging programme to help the NHS make appropriate use of genetic knowledge and technology as it became available and an announcement of £50m to fund this programme. The Government will, this year, conduct a review of progress following this investment and both the HGC and our Consultative Panel will play a significant role in helping to recognise the undoubted successes of the programme and identify some of the areas which could benefit from more attention.



This year, we published our views on the complex issues relating to genetics and reproductive decision-making. In *Making Babies: Reproductive decisions and genetic technologies*, we attempted to work through many of the questions and issues people having a baby face today and considered the current and future position with regard to screening, preimplantation genetic diagnosis (PGD) and other reproductive therapies. With the accelerating pace of genetic research, the choices open to couples experiencing fertility problems or families with a history of genetic illnesses are now considerable and increasing. However, these new possibilities bring with them new concerns. We have to balance the need to assure reproductive autonomy – the rights of parents to make their own decisions – with the welfare of the child and the wider interests of society.

Our report provides a framework for future debate and policy decisions within the UK. Both *Making Babies* and the results from the Commission's earlier consultation on this issue show that these are issues on which society is divided and holds deep-rooted views; there is therefore a clear need for continuing public debate in this area.

A crucial element of our continued advice to Government is reflecting public views and concerns on particular genetic topics, which is why we are committed to promoting debate and listening to the public in an open and transparent way. We also strive to contribute to the debate, sometimes by commenting on topical issues as they have arisen – for example – by responding directly to the media and others, by posing direct questions to members of the public on our website and inviting a response.

One of our projects in the forthcoming year is a public dialogue event looking at the use of genetics in criminal investigations. Indicators suggest that the public are generally supportive of DNA use but we want to examine more closely the social and ethical consequences of expansion of the National Database and the further uses to which DNA might be put and we want to draw the public in to share the debate with us.

At the end of 2005 we reached the end of our second 3-year 'term of office' and there were a number of changes to our membership. We were pleased to welcome several new faces – Frances Flinter, Christopher Higgins, Rosemary Leonard, Lola Oni, Alice Maynard, Sarah Cunningham-Burley and Ros Gardner – who have all made a valuable contribution to the Commission over their first few

Chair's introduction

months. These changes gave us an opportunity to review how we work. We wanted to be able to keep track of all of the topics that had come onto our radar, as well as take forward important new work. We, therefore, have streamlined the structure of our Monitoring and Working Groups, and reorganised some of the responsibilities of the Commission amongst them. For each of these we have identified Members to lead on each issue and make sure that these topics remain high on our agenda and that the Commission can successfully participate in wider discussions across Government and between external organisations.

All these changes did of course mean that we had to say goodbye to some of the original members of the Commission and I would like to offer my personal thanks to them. Bill Albert, Hilary Newiss, Martin Richards, Veronica van Heyningen and Geoff Watts helped to shape the work and ethos of the HGC from its inception and I am greatly indebted to them.

I hope that you find this report useful and informative and that we can count upon you to be part of our future work and consultations.

Helena Kennedy

Baroness Helena Kennedy
Chair, Human Genetics Commission



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Summary of Key Achievements

This section provides a summary of the key achievements mentioned in this annual report for the period April 2005 – March 2006.

- The HGC's *Making Babies* report

In January 2006, the HGC published *Making Babies: reproductive decisions and genetic technologies*, a report covering the reproductive choices facing couples who want to have children. The Commission looked at the current and future position with regard to screening, PGD and other reproductive therapies. Like all HGC reports, *Making Babies* can be read or downloaded from the HGC website.

- The HGC welcome new Members

December 2005 saw the appointment of seven new HGC Members. The new Members – Dr Frances Flinter, Professor Christopher Higgins, Dr Rosemary Leonard, Ms Lola Oni, Ms Alice Maynard, Professor Sarah Cunningham-Burley and Mrs Ros Gardner – were welcomed by the then Health Minister Jane Kennedy MP and Science Minister Lord Sainsbury.

In a statement, Jane Kennedy MP said:

“The HGC brings broader social, ethical, legal and economic considerations to one of the most exciting and fastest evolving areas of science and technological development. Since its formation over five years ago, it has built up a strong reputation for the quality and balance of its advice, and this is greatly valued by Government. These new appointments will enable it to continue to draw on a broad and experienced membership in future.”

- National Forum of Ethics Councils

The Commission jointly hosted the European Commission's Forum of National Ethics Councils (NEC) in November with the Nuffield Council on Bioethics. The main topics for discussion at the event were public health and the tension between autonomy and public good, and the forensic use of databases.

- Consultative Panel Event and re-introduction of newsletter

Last autumn, the HGC held a daylong Consultative Panel event in London. It was a relaxed and informative day with Panel members providing feedback on the draft recommendations of the Commission's report on genetics and reproductive choice, the work of the HGC so far, as well as giving their ideas for future work. Following feedback at the event, the Secretariat has also reintroduced the Consultative Panel newsletter.

- Feeding into Government policy relating to genetic issues

The unique position held by the HGC, to advise Government on human genetics with a particular focus on the social, ethical and legal issues means it is continually approached to contribute to consultations and debates relating to genetic issues. Over this reporting year, the Commission has contributed to many areas of Government policy which either directly or indirectly relate to genetics including the introduction of electronic patient records, paternity testing, the retention and storage of fingerprints and DNA samples in Scotland and many others. For more information about this aspect

Summary of Key Achievements

of the HGC's work, please turn to Annex E of this report, which details their published responses and memoranda.

● Genetic Discrimination

The potential for discrimination against individuals who are affected by a genetic condition has long concerned the Commission and this reporting year was no exception. In June 2005, the Commission welcomed the Information Commissioner's Employment Practices code, which contained a number of the suggested recommendations that HGC had made relating to genetic testing in the workplace, including a specific recommendation that HGC should be informed of any plans to use genetic testing for employment purposes.

The Commission has also taken forward a piece of work requested by Science Minister, Lord Sainsbury, investigating the prevalence of genetic testing in the work place and has fed into the Government's Equalities Review, chaired by Trevor Phillips. Members will report back to Ministers and present their findings on the HGC website in due course.

● Additional HGC input into the work of the National DNA Strategy Board and new ethics group

Since 2002, a Commission Member has sat as a HGC representative on the National DNA Database Strategy Board – the Board which oversees the operation and management of the police DNA database. This year, following discussions between the HGC, the Home Office and the Chair of the Strategy Board, Chief Constable Tony Lake, the Home Office invited the HGC to nominate another of its Members to sit on the Board. It also agreed to include two lay members on a new ethics committee, which would oversee research and development proposals relating to the Database and asked for the HGC's assistance in setting up the committee.

● HGC website

Since the re-launch of the HGC website in February 2005, we have continued to populate it with new information and visitor numbers to the site have continued to increase. For more information on any of the issues you read about in this report, please visit the HGC's site:
www.hgc.gov.uk



Our Meetings held between April 2005 and March 2006

Continuing our commitment to holding our main meetings in public, we once again visited a number of locations this year. The minutes of our meetings and reports of proceedings are published on our website (www.hgc.gov.uk). Podcasts of our main Plenary meetings are also available on the website.

May 2005 – Glasgow

In May 2005, we held our 20th plenary meeting and our first in Glasgow. The meeting began with an informative presentation on genetic services in Scotland by Professor J Michael Connor, a clinical geneticist who holds the positions of Director of the West of Scotland Regional Genetics Service and Professor of Medical Genetics at the University of Glasgow. He spoke in detail about the types of genetic screening that were available in Scotland, including newborn screening, screening for chromosome disorders and for single gene disorders.

Following the presentation, there was a discussion concerning the Science and Technology Committee's report, *Human Reproductive Technologies and the Law* and in particular, the recommendations relating to the Human Fertilisation and Embryology Authority and the Human Genetics Commission and the possible creation of Regulatory Authority for Tissue and Embryos.

The following day, the Commission held an information gathering session on the issue of consent.

September 2005 – London

Our September meeting was held in London where the group discussed the planned revision of the UK Health Departments' *Code of Practice and Guidance on Paternity*, which was published in 2001 and would become out-of-date with the enactment of the Human Tissue Act 2004. The meeting was also the last for Dr Susan Johnson and Dr Stephen Singleton. The Chair thanked them warmly for their support and overall contribution to the work of the Commission.

The following day we held our first Consultative Panel event since 2003. It was a relaxed and informative day with Panel members providing feedback on the draft recommendations of the Commission's report on genetics and reproductive choice, the work of the HGC so far, as well as giving their ideas for future work. Our thanks go to all Panel members who took part and who continue to make an important contribution to the Commission. For more information about the day, please see page 18.

November 2005 – Southampton

During our November meeting in Southampton, we said goodbye to a number of longstanding members of the Commission: Dr Bill Albert, Ms Hilary Newiss, Professor Martin Richards, Mr Geoff Watts and Professor Veronica van Heyningen. The Chair thanked them for their help, advice and support over the past six years.

The meeting began with an excellent presentation from Professor Jonathan Montgomery, Professor of Health Care Law at the University of Southampton, entitled *Children, Parents and Genetics: Entangled Interests?* Later, the group had an in-depth discussion about the final draft of the HGC report on genetics and reproductive choice.

The information gathering session held the next day was on the topic of genetics and aging. Speakers held interesting and sometimes opposing views about the relationship between our genes and how we age, which led to a lively debate. More information about this and other information gathering sessions can be found on the HGC website.

Our meetings

February 2006 – London

February's meeting was held in London. After having said goodbye to so many of our members at the previous plenary we were pleased to welcome new members Dr Frances Flinter, Professor Christopher Higgins, Dr Rosemary Leonard, Ms Lola Oni, Ms Alice Maynard, Professor Sarah Cunningham-Burley and Mrs Ros Gardner.

In this Plenary we discussed the launch of the Making Babies report in January. The launch was well attended and received favourable reports from the media. Baroness Kennedy offered special thanks to Professor Martin Richards who chaired the working party for this report.

A large part of this Plenary was spent discussing the Commissions future work plan and the organisation of the monitoring groups in light of the recent membership changes. The group also discussed issues of interest that they would like to look at more carefully over the coming year. It was agreed that there was a need to revisit the 2003 report *Genes Direct* in order to see how many of the recommendations the HGC had made had been implemented. It was also decided that, over the course of the coming year, the Commission would focus on genetic discrimination – an issue that had previously been flagged up by the Consultative Panel as an area of concern. With regards to the Monitoring Groups, the discussion focussed on their composition as well as the range of issues each group had responsibility for and whether restructuring would mean they could work more productively.

Following much discussion, the Commission agreed that the Business Committee would take on the function of the Public Involvement Monitoring Group and that the role of horizon scanning would be the responsibility of the chairs of each Monitoring Group, rather than one individual Monitoring Group. It was agreed that the remit of the Identity Testing Monitoring Group was disproportionately large and so the issue of paternity testing was transferred to the Genetic Services group. Finally, it was agreed that the Genetic Research Database Monitoring Group should be renamed the Database Monitoring Group as its interest was broader than merely research databases.

To read more about the restructuring, you can view the February 2006 plenary minutes in the plenary section of the HGC website, which can be found at:
http://www.hgc.gov.uk/Client/Content_wide.asp?ContentId=145



Making Babies: Reproductive decisions and genetic technologies

In January, we published our report on genetics and reproduction, *Making Babies: Reproductive decisions and genetic technologies*.

The work for this report began in 2003 and was undertaken by a Working Group that was co-chaired by Baroness Helena Kennedy and Professor Martin Richards. This Working Group was set up in May 2003 to consider the issues around new and developing technologies associated with human reproduction and their implications for society. It superseded the earlier Scoping Group on Genetics and Reproduction.

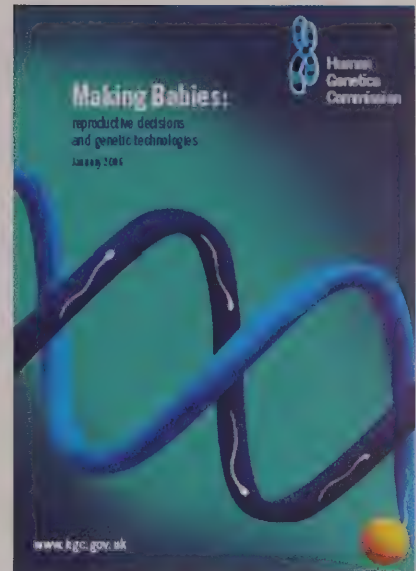
As with all of the Commission's work, public involvement was a key feature of this report and to inform our discussions we heard from a wide range of organisations and began a formal consultation exercise in July 2004. Almost 200 responses were received and brought to our attention many well-reasoned arguments in favour of a range of positions. In addition, a youth Citizens' Jury was able to feed into this work. This was organised by the Wales Gene Park with the University of Glamorgan and Techniquet in September 2004. The jury of 16 -19 year olds addressed the question: 'Designer Babies: what choices should we be able to make?'. We were also able to discuss this topic with our invaluable Consultative Panel in September 2005 to examine our recommendations and conclusions with them.

During the course of this work, many other organisations were having parallel, relevant discussions about these issues, for example the Science and Technology Committee report on human reproductive technologies and the law and the Department of Health's review of the Human Fertilisation and Embryology Act. The Commission fed these discussions into their work.

The Working Group discussed the tension between societal intervention and personal liberty but felt that there must be times when we say "your choice has negative consequences for our society as a whole". The main conclusions from the report were:

- That these are issues on which society is divided and where views are deeply felt. The Commission reached consensus on many issues but some differences remained.
- For real choice to exist, people must know that they are free to decline screening and that they will be properly supported in that decision and thereafter, should any newborn have a genetic problem. A culture which does not acknowledge that all humanity has value and that each one of us is capable of contributing to the social good is a culture which is abandoning its ethical core.
- As technology develops and the range of tests increases, a careful assessment should be made as to the benefits and desirability of such testing.
- There is a need to follow up children resulting from new technologies such as PGD (preimplantation genetic diagnosis) and IVF.
- Many procedures like PGD are still in the very early stages of use and available to extremely small numbers of people. "Designer babies" are not around the corner and probably never will be.

To download a copy of the report please visit the HGC's website
<http://www.hgc.gov.uk/Client/document.asp?DocId=112&CategoryId=8>



Key Pieces of Work

Working Group Terms of Reference

1. To collate information, take evidence and consider past, current and future developments in genetic services related to reproduction within the current legal framework and in terms of the technology and public attitudes towards its use.
2. To examine, in particular, advances as they relate to prenatal genetic screening services, prenatal genetic diagnosis and preimplantation genetic diagnosis.
3. To work with existing bodies responsible for regulating and/or advising Government on genetics and reproduction including the National Screening Committee and the Human Fertilisation and Embryology Authority.
4. To work with HGC groups as appropriate to develop strategies for public consultation and discussion, to develop the working group's knowledge about genetic services and horizon scan in the area of genetics and reproduction.
5. To contribute to and/or respond, where appropriate, to emergent national debates about genetics services and their implications for reproductive decision making.
6. To prepare and publish a consultation document and to consider other methods for obtaining the views of stakeholders and others.
7. To identify from consultation and deliberation, sound ethical principles appropriate to genetic advances and services related to reproduction.
8. To publish a report identifying our conclusions and recommendations pertaining to the ethical principles on genetic advances and services related to reproduction and to communicate these to Health & Science Ministers.

Working Group members

Baroness Helena Kennedy (Co-chair)
Martin Richards (Co-chair)
Bill Albert
Brenda Almond
Elizabeth Anionwu (to July 2004)
John Burn (to April 2005)
Angus Clarke (from Feb 2004)
Heather Draper (Co-opted)
Frances Flinter (Co-opted)
Hilary Harris (to July 2004)
Michael Harrison (from Sept 2004)
John Harris
Iona Heath (from Sept 2004)
Susan Johnson (from Sept 2004 – Sept 2005)
Alastair Kent
Suzi Leather (ex officio Member)
Christine Patch
Peter Sayers
Veronica van Heyningen

Full details about the working group, including minutes of meetings, can be found on the HGC website at <http://www.hgc.gov.uk/Client/Content.asp?ContentId=262>

National Forum of Ethics Councils

The Commission was honoured to jointly host the European Commission's Forum of National Ethics Councils (NEC) in November with the Nuffield Council on Bioethics. This provided the Commission with an excellent opportunity to discuss issues with delegates from different countries who often approach the issues from a different perspective.

The main topics for discussion at the event were public health, specifically the tension between autonomy and public good, and the forensic use of databases. At the event, Sir John Sulston, HGC Vice-Chair, gave an interesting presentation on the UK National DNA database. Following his presentation, the Coordinator of the EU project on ethics and biometrics, Professor Mordini, spoke about the ethical implications of biometrics. These presentations generated discussions about:

- inclusiveness, and who samples should be taken from;
- which procedures were least intrusive;
- how systems can cope with cross-border flow;
- privacy of individuals, especially when a near match on the database can reveal details of a relative, and
- concern about unethical technology creep.

Delegates found the discussions very useful. Further details about the meeting can be found on the European Commission website:

http://europa.eu.int/comm/research/science-society/home_en.cfm

The Forum was established in 2002 and consists of the chairs and secretaries of national ethics councils. Meetings take place every 6 months. The Human Genetics Commission was asked to jointly host this event with the Nuffield Council on Bioethics because the UK held the EU Presidency and the UK does not have a national ethics council. The event was held in London on 18 November 2005.



Key Pieces of Work

Consultative Panel

In 2001, the HGC set up a Consultative Panel of people affected by a genetic disorder. The Panel, which is made up of about 100 people with direct experience of living with genetic disorders, acts as a sounding board for our reports and recommendations, as well as giving us insight into their concerns about genetic issues.

Much of the Panel's work is by correspondence, with Panel Members being sent summaries of reports we are writing or issues we are discussing for comment. It is planned that annual meetings will also be held to allow Panel Members to meet with Commissioners and to discuss issues in depth.

Thank you very much for an excellent day. I would like to thank the Panel, on behalf of the whole Commission, for coming and for all the hard work and valuable comments you have given both today and over the years. Your opinions do matter as they help enormously to shape our work. We very much look forward to continuing to work with you over the coming months and years.

Sir John Sulston, Vice-Chair of the HGC. Consultative Panel Event, September 2005.

The Panel includes people who have experience of single gene, chromosomal or multifactorial disorders, which may have become apparent in either childhood or adulthood. Some people are affected themselves or are carriers, some have experience as a parent of a child affected by a genetic disorder and some are carers for someone in their family who is affected. Membership has a wide age range and includes people who live in England, Scotland, Wales and Northern Ireland. We established the Panel because we wanted to hear from people directly affected by a genetic disorder so that they can help us make informed decisions. We need to learn from people who know about the reality of living with a genetic disorder, their experience in deciding whether to take a genetic test and whether, for example, they have concerns about insurance and employment issues. Our hope was that the Panel would let us do this in a way that was both useful for the HGC and rewarding for those who participate.

The Panel has been a tremendously valuable resource for us. Since it was set up, members have assisted us with several consultations, meetings and the overall work-plan of the Commission. This year was no exception and Panel Members were of particular help with our work on reproductive choice and discrimination.

In September, the Commission held its second daylong, Consultative Panel event. Over half the Consultative Panel and nearly all HGC Members attended the event. The meeting was an opportunity for the Panel, once again, to meet HGC and other Panel Members and to hear about and discuss the Commission's forthcoming areas of work. The Commission were also keen to learn the Panels' views on the conclusions of the HGC's Working Group on Genetics and Reproductive Decision-making, which would eventually go towards their *Making Babies* report.

The meeting began with a couple of short presentations in the morning followed by group discussions in the afternoon. A summary of the feedback given by the Panel following those group discussions can be found at Annex E. Overall, the event was a great success for all involved and HGC Members announced that they hoped to hold such an event annually. They also committed that they would re-launch the quarterly Consultative Panel Newsletter in order to maintain a high level of engagement and ensure that the Panel could feed-in ideas more frequently.

More information on the Consultative Panel can be found on the HGC's website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=375>

HGC Work Plan 2006/2007

This work plan sets out the major pieces of work that the Human Genetics Commission (HGC) plans to take forward over the next 18 months, until autumn 2007. These plans reflect a desire to take a proactive role, responding to issues in a timely manner as they arise, rather than producing lengthy reports. In addition to the pieces of work identified, the Commission's Business Committee and monitoring groups will continue to operate and suggest further specific issues to monitor. As the Secretariat returns to full complement, the Commission also plans to become more engaged in research and intellectual property issues.

The Commission's current work falls into four main areas:

- Genetic Discrimination
- Public Involvement
- Forensic Use of DNA
- Follow up from previous work

Genetic Discrimination

The HGC's report *Inside Information: Balancing interests in the use of personal genetic data* (2002) set out the Commission's concerns relating to genetic discrimination. Following on from this firm foundation, the Commission will be inputting into a number of Government Reviews relevant to this area this year, including the Equalities Review, led by Trevor Phillips, and the Discrimination Law Review. The Commission will also build on the request from Lord Sainsbury to find out whether genetic testing is happening in the workplace and produce an easy to understand information leaflet in the autumn on genetics and employment, covering all the relevant issues.

While a large proportion of the Commission's work in this area to date has focussed on the non-medical use of genetic data, the Commission will also focus on the medical use of this data and will monitor how genetic information will be processed and handled with the forthcoming electronic patient record system and the National Programme for IT.

Public Involvement

Involving the public remains an essential part of the Commission's work. Over the next 18 months the Commission plan to hold 2 major events:

- a Citizens' Jury, and
- a Consultative Panel event.

The HGC is keen to embark on a new public involvement exercise and find out the view of the general public on acceptable uses of DNA in a forensic setting. The HGC feel that a Citizens' Jury will be an excellent way to find out this information and aim to hold one later in 2006.

The Consultative Panel continues to be an invaluable resource to the Commission. The HGC will build on the success of last year's Consultative Panel event and hold another one later in 2006. The Commission will also engage the Panel in more of their discussions through the Consultative Panel newsletter.

The Commission will continue to operate in an open and transparent way and will hold its main meetings across the UK. It will also continue to invite members of the public to attend these meetings. The HGC will also continue to populate its revised website with meeting details and new information content.

HGC Work Plan 2006/2007

Relationship and Identity Testing

In addition to the work on the Citizen's Jury, the HGC will continue to be involved with the National DNA Database Strategy Board. Two Commissioners now sit on this board. The Commission anticipate that over the next year, the recommendation in *Inside Information* to establish a separate research ethics committee to approve research requests involving the National DNA Database will be put into place. HGC will have a strong role in this committee.

The Commission will also be providing significant input into the revision of the Health Department's code of practice on paternity testing. The document needs to be updated to reflect the Human Tissue Act and the offence of testing DNA without consent (the so-called DNA theft clause), first suggested by the HGC, which will come into force in September 2006.

Follow up from previous work

Over the past 6 years, the HGC has produced 4 major reports. As developments in these areas move on, it is important to review the recommendations that the Commission has made and also look to see where and how the Commission has made most impact. The Commission will begin by looking at its *Genes Direct* report. It is 3 years since it published its report on direct to public genetic testing and some areas of this work have not developed as initially expected.

This work, as with all HGC work, will of course adopt a UK perspective where the Commission will take into account the legal and other differences between Scotland, Northern Ireland, England and Wales, and the status of devolved and non-devolved matter.



The HGC Business Committee

The Business Committee is an important driver for the workings of the Commission. It is the forum that shapes much of HGC business and oversees its public engagement agenda.

The role of the Business Committee is:

- to provide a responsive executive structure so that HGC can react to developments quickly and involve the Membership as fully as possible;
- to liaise with lead members between plenary meetings and continue liaison with key organisations such as the Nuffield and the Wellcome Trust;
- to oversee external communications;
- to oversee press/communications arrangements and the HGC website content, and
- to provide editorial oversight of the Consultative Panel newsletter and the HGC annual report.

The Committee meets every month, except those months in which plenary meetings are scheduled and the month of August. Membership of the Committee entails a regular commitment on the part of Commissioners and so it operates a rolling membership.

Journalist and presenter, Geoff Watts, led the Committee for almost three years before leaving the Commission in December 2005. Sir John Sulston took over as Lead member and the Committee gained several new members from the fresh intake of Commissioners in January. Further, it was agreed at the HGC Plenary meeting in February that the Business Committee would take on responsibility for all public involvement work and a special satellite Working Group would be set up to oversee the arrangements for the HGC Public involvement exercise on the forensic use of personal information.

For more information on the Business Committee visit the HGC website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=261>

Membership during the reporting period

John Sulston (Lead from January 2006)

Geoff Watts (Lead until December 2005)

Celia Brazell (until December 2005)

Sarah Cunningham-Burley (from January 2006)

Frances Flinter (from January 2006)

Ros Gardner (from January 2006)

Alastair Kent (from January 2006)

Rosemary Leonard (from January 2006)

Peter Sayers

Veronica van Heyningen (until December 2005)

HGC Monitoring Groups

Intellectual Property and Genetics Monitoring Group

The issue of patents, intellectual property and genetics continues to be debated widely in many national, regional and international forums. In February 2003, HGC established an Intellectual Property and Genetics Monitoring Group in order to monitor the issues including European and other international developments of relevance to the UK.

Members during the reporting period

Christopher Higgins (Lead from January 2006)

Hilary Newiss (Lead until December 2005)

Brenda Almond

Celia Brazell

Alastair Kent

John Sulston

The role of this group is primarily to build on the work done by other bodies in fostering debate, and to monitor developments and publications by other bodies.

Members of the group have regular email contact to monitor the work of key stakeholders, new research findings as well as to begin to form views on a variety of topics. This is then reported to the main Commission at its plenary meetings.

The issues we look at include:

- Ethical concerns
- Should genetic material be patentable?
- Ethics and gene patents
- Application of the law
- Competition and access to information
- Informed consent, donor identification and confidentiality
- Other issues: stem cells, incentives

The group has considered several particular developments this year including the development of the Biobank Intellectual Property policy and the decisions on European patent rights to two genes linked to breast cancer. The group has also expanded the information that it has on this issue on the HGC website. The group is currently considering its focus for 2006 and is hoping to recruit a co-opted Member to provide specialist legal advice on these issues.

For more information on the Intellectual Property and Genetics Monitoring Group visit the HGC's website: <http://www.hgc.gov.uk/Client/Content.asp?ContentId=256>

Database Monitoring Group

The Group was initially formed in 2003 to continue to track developments in the UK Biobank. Following the publication of *'Inside Information'*, which addressed general research issues like consent and feedback, the HGC were asked to submit a formal memorandum on the UK Biobank. The Commission continues to hold meetings and informal liaison meetings with the Biobank funders and met with Biobank's Ethics Governance Council in July 2005.

The group also considers some of the wider issues with research databases and the main topics in this area that HGC continue to pursue include:

- Ensuring that consent is informed and covers questions like feedback and intellectual property
- Ensuring strict confidentiality, by effective coding, anonymisation or encryption and by controlling access by groups such as the police
- Maintaining public confidence, particularly ensuring that large public research databases remain a trusted public resource
- Promoting realistic expectations of the pace of scientific and medical research and the role of partnerships between public and commercial research

At the February plenary meeting, new Member, Sarah Cunningham-Burley agreed to succeed Celia Brazell as the Lead of the Group. At this meeting it was also agreed that the Research Database Monitoring Group should be renamed the Database Monitoring Group as its interest was broader than merely research databases.

For more information on this Monitoring Group visit the HGC website: <http://www.hgc.gov.uk/Client/Content.asp?ContentId=258>

Membership during the reporting period

Sarah Cunningham-Burly (Lead from January 2006)

Celia Brazell (Lead until September 2005)

Stephen Bain

Angus Clarke (from January 2006)

John Harris

Christopher Higgins (from January 2006)

Hilary Newiss (until December 2005)

Lola Oni (from January 2006)

Martin Richards (until December 2005)

Veronica van Heyningen (until December 2005)

HGC Monitoring Groups

Horizon Scanning Monitoring Group

An important role of the HGC is to provide Government with advice on advances in human genetics and their implications for healthcare as well as the broader social and ethical issues. The Horizon Scanning Monitoring Group has continued its work by considering a number of important issues including advances in technology, pharmacogenetics, stem cell research and technology, aging research, nanotechnology and consent issues. Over time there will be some surprising new issues raised by the availability of genetic testing and the Commission needs to be poised to advise on these.

This Monitoring Group has played an important role in advising the Commission on what issues it should consider in its information gathering sessions and was involved in this year's events on consent and genetics and aging.

In September 2005, the HGC Secretariat met with the Government's Horizon Scanning Centre. The Centre have established a database that attempts to offer estimates of what will happen in science over the next 50 years and when. The system is able to look at where there are potential skills deficiencies in these areas that might slow these developments down. The HGC and the Horizon Scanning Centre agreed to keep in touch about the database and to assist where possible.

At the February plenary meeting, the Commission discussed the role and purpose of this Group and decided that horizon scanning should be the responsibility of the Commission as a whole and not centralised in one Group. It was agreed that the Commission would pursue new ways of horizon scanning, for example, the Secretariat could arrange a one-day annual horizon scanning session where topics of interest could be explored. Chairs of Monitoring Groups would raise new issues as they arose. Further, Commissioners could also see a role for the Business Committee in that it provides an opportunity for Members to bring genetic issues which might be of interest to the Secretariat's attention.

For more information on this Monitoring Group visit the HGC's website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=255>

Membership during the reporting period

Veronica van Heyningen (Lead, until December 2005)

Celia Brazell

John Harris

John Sulston

Genetic Discrimination Monitoring Group

This Genetic Discrimination Monitoring Group was formed in 2003 to further the work on genetic information and its possible use in insurance and employment. The members of the Group hold regular meetings to identify work for the Commission and to monitor the work of other key stakeholders and new research findings.

In July, Bill Albert stood down as Lead of the group and John Sulston took this role over from him. This marked a significant change for the group as Bill had been the Lead since the group's inception. At this meeting, the Group thanked Bill for all his hard work with this topic.

This has been a busy year for the group and they have held several teleconferences and a meeting to discuss their work.

The use of test results for familial breast cancer for non-medical reasons has attracted a lot of debate this year in the media. Following the announcement of the extension of the new Concordat between the Association of British

Insurers and the Government that extends the moratorium on use of genetic tests until 2011, the group has turned its attention to genetics and employment. However, the Commission still continue to attend Genetics and Insurance Committee (GAIC) meetings and was involved in a GAIC public meeting on breast cancer, diagnosis and treatment in 2005. Following a joint meeting between the Commission and GAIC at the end of 2004, Paul Debenham produced a paper on the possible use of biomarkers, now and in the future which is available on the HGC website. Concerns have been expressed that insurers would be able to use biomarker tests as a substitute to genetic tests, thus bypassing the moratorium. HGC will continue to monitor this issue.

In June, the Information Commissioner issued the Employment Practices code. HGC's response to the consultation on this had significant influence in the report. The final code contains a number of the Commission's suggested recommendations relating to genetic testing in the workplace, including a specific recommendation that HGC should be informed of any plans to use genetic testing for employment purposes. This was one of the Commission's big achievements this year. This code will offer greater protection to employees.

Genetic testing in employment had enhanced publicity in 2005 following the case of a worker in Germany being denied civil servant status because she had a predisposition to Huntington's disease. Lord Sainsbury, the Science Minister, wrote to the Commission in September to ask them to conduct a brief review into the prevalence of genetic testing in the workplace. The Commission has written to several organisations and hopes to present the results of its findings in the Spring. The Commission does not have evidence to date that any similar situations to that in Germany have occurred in the UK. An update on this piece of work can be found on the HGC website.

Membership during the reporting period

John Sulston (Lead, from July 2005)

Bill Albert (Lead until July 2005 and member until December 2005)

Stephen Bain

Ros Gardner (from January 2006)

Michael Harrision

John Harris

Iona Heath

Christopher Higgins (from January 2006)

Alastair Kent

Rosemary Leonard (from January 2006)

Alice Maynard (from January 2006)

Martin Richards (until December 2005)

Peter Sayers

Patrick Morrison (co-opted)

HGC Monitoring Groups

The Group has also fed into the Government's Equalities Review and Baroness Kennedy met with its Chair, Trevor Phillips, to discuss genetic discrimination issues. The review published an interim discussion document in March and the Commission will issue a formal response to this which will appear on the HGC's website.

The Group has also been monitoring how genetics are going to be used with electronic patient records and this will continue into the next reporting year.

Over the coming reporting year the Discrimination Monitoring Group will be seeking to influence the Government's review of discrimination law and developing an information guide and a voluntary understanding about genetic testing and employment. The Commission also plans to hold an information gathering session on genetics and discrimination in May 2006.

For more information on this Monitoring Group visit the HGC's website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=254>

Public Involvement Monitoring Group

Engaging the public in issues relating to genetic science has always been a principal aim of the HGC. Our terms of reference clearly state that we should:

“develop and implement a strategy to involve and consult the public and other stakeholders and encourage debate on the development and use of human genetic technologies and advise on ways of increasing public knowledge and understanding.”

The Group was formed in 2003 to co-ordinate the ways in which the Commission involves people in its work. Monitoring Group members held meetings or discussed issues via email to oversee HGC's activities relating to public involvement, in particular to promote debate and achieve effective representative dialogue with a wide cross-section of people. The main areas overseen by the Group were:

- Public Involvement Strategy
- HGC's Consultative Panel
- HGC's Press Office
- Website
- Liaising with other organisations
- Relevant publications

We have always strived to conduct HGC business in public and we continue to make regular trips to cities across the UK in order to ensure that people in other parts of the country have an opportunity to visit our public plenary meetings. We also recognised the importance of an effective website for the Commission as a crucial resource in this respect and have worked hard over the last 18 months to improve the format and content of the site.

In September, the Commission held its second daylong, Consultative Panel event. The meeting was an opportunity for the Panel, once again, to meet HGC and other Panel Members and to hear about and discuss the Commission's forthcoming areas of work.

A summary of the feedback given by the Panel following those group discussions can be found at Annex E. Overall, the event was a great success for all involved and HGC Members announced that they hoped to hold such an event annually.

It was following this meeting that the Public Involvement Group and the Business Committee agreed to re-launch the quarterly Consultative Panel Newsletter in order to maintain a high level of engagement with the Panel. A copy of the first Newsletter can be found at Annex E for your interest.

For some time, the Commission has been keen to hold a public engagement exercise on a genetics related topic, which it felt was of real significance to the British public. Members considered several topics and concluded that the current and future use of DNA for forensic purposes, specifically, the National DNA Database, was the most pressing issue for consideration.

Members during the reporting period

Geoff Watts (Lead until December 2005)

Paul Debenham (until February 2006)

Alastair Kent (until February 2006)

Christine Patch (until February 2006)

Peter Sayers (until February 2006)

HGC Monitoring Groups

They concluded this for several reasons. Firstly, the use of DNA for forensic purposes is a practice which can potentially affect all UK citizens at some time in their lives and the likelihood of this is increasing given the increased use of DNA information by police authorities for criminal intelligence purposes. In addition, following recent natural disasters, such as the Tsunami, and the terrorist bombings in London, there is an increased public awareness of what DNA is and how it can be used to identify individuals, including those who are either innocent or guilty of a crime or a victim of disaster.

Further, some external bodies have also recommended that the database be subject to greater public scrutiny. More information on the growing political desire for debate can be found in the Identity Testing Monitoring Group pages but Geoff Watts, the long time Chair of the Public Involvement Group was particularly struck by a comment that Commissioner of the Metropolitan Police, Sir Ian Blair, made in his 2005 Dimpleby lecture relating to public consultation on police powers that:

"It is a time for politicians and commentators of every stripe and opinion actively to consider how citizens can be involved in a debate about what kind of police service we want."

The Commission feels strongly that this matter has not yet been subject to significant public debate and are arranging to ask an informed group of UK citizens – having considered the key issues involved – their views on the current and future use of DNA for forensic purposes, specifically, the National DNA Database.

The HGC Secretariat has sought the advice of the OST Science and Society Directorate and the Sciencewise programme regarding the feasibility, practicability and likely costs of holding such an event and a Working Group has been set up to oversee this project. The whole Commission sees this exercise as an extremely worthwhile endeavour.

At the Plenary meeting in February 2006 it was agreed that there was not a need for a separate Public Involvement Monitoring Group and that the important function that it performed should become a integral part of the Business Committee's work.

For more information on this Monitoring Group visit the HGC's website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=261>



Identity Testing Monitoring Group

An important aspect of the Commission's role is to provide advice to inform Ministers' decisions on broad, social and ethical issues relating to human genetics. It was within this context that in June 2001, we visited the Forensic Science Service to learn about the organisation and management of sampling, profiling and the National DNA Database. Following that, in May 2002, we published *Inside Information – Balancing interests in the use of personal genetic data*, which contained the following recommendation:

“We recommend that, at the very least, the Home Office and ACPO establish an independent body, which would include lay membership, to have oversight over the work of the National DNA Database custodian and the profile suppliers.”

Further, we recommended that: *“In the short term the Home Office and FSS introduce an independent research ethics committee, to approve such research.”*

Following publication of that report, the National DNA Database Strategy Board invited us to put forward one of our members to sit on the Board and this arrangement has continued to this day. Currently, Professor Stephen Bain represents the Commission on the Board and keeps the Commission abreast of progress relating to the NDNAD Strategy Board at our regular plenary meetings.

Much has happened in this area over the past 18 months. In March last year, the HGC were invited by the Science and Technology Committee to comment on evidence given to them regarding the guardianship of the National DNA Database. The HGC response reiterated the recommendations contained in *'Inside Information'* – that there should be an independent body, which would include lay membership, to oversee the work of the NDNAD custodian and that an independent research ethics committee should be set up to approve research. The Science and Technology Committee report supported the HGC's view and urged the Home Office to implement the recommendations as part of the revision of the custodianship arrangements of the National DNA Database. In addition, Baroness Kennedy wrote to the new Chair of the National DNA Database Strategy Board, Chief Constable Tony Lake, asking him to take on board the recommendations in *'Inside Information'*, relating to the database.

As a result of these developments, the Home Office agreed to include two lay members on the new board, who would be nominated by the HGC. They also agreed to set up a separate ethics committee to look at research and development, which would include the two lay members. Final arrangements for the new Strategy Board are currently being made and it will be set up later this year.

The Identity Testing Group has also worked hard this year to proactively engage with stakeholders on this issue, be they in the media, Government departments or other scientific ethical bodies. It has responded to two important developments in Scottish policy in relation to the forensic use of DNA. The first was Scottish Executive's draft proposals on the collection and retention of DNA samples

Membership during reporting period

Steve Bain (Lead)

Brenda Almond

Paul Debenham

Frances Flinter (from January 2006)

Christopher Higgins (from January 2006)

Rosemary Leonard (from January 2006)

Alastair Kent

Lola Oni (from January 2006)

Hilary Newiss (until December 2005)

Christine Patch

Peter Sayers

HGC Monitoring Groups

and fingerprints in Scotland. The second, was the DNA amendment to the Police, Public Order and Criminal Justice (Scotland) Bill lodged by Paul Martin MSP in February. Both are enclosed at Annex E for your interest.

The Group has also contributed to a Nuffield Workshop on the forensic use of information and presented information on the topic at the National Forum of Ethics Councils, held in London in November.

There were also developments in another of the Identity Testing Group's responsibilities. The Group is concerned with relationship testing and issues around consent to testing. Indeed, the Government's announcement in the Genetics White Paper in 2003 that the Human Tissue Bill would introduce a new offence of testing an individual's DNA without their consent followed a Human Genetics Commission recommendation to change the law to prevent non-consensual genetic testing, including paternity testing. The Commission therefore welcomed section 45 of the Human Tissue Act 2005, which made it an offence to have DNA for the purposes of analysing DNA without consent and is pleased that this change in the law is clearly set out in the Human Tissue Authority's code of practice.

This year the Group responded to the new Human Tissue Authority's draft code of practice – *Code of Practice 1: Consent* (enclosed at Annex E). Further, the HGC was asked by the Department of Health for views on the revision of the Government's Code of Practice on Paternity Testing and to consider how best to prevent testing companies from straying into practices that the section 45 non-consensual DNA testing offence is designed to prevent.

The *Code of Practice and Guidance on Genetic Paternity Services* will be reviewed before the Human Tissue Act comes into force in September 2006. The Identity Testing Group has begun this work, however, in February 2006, it was agreed that it was appropriate for the Genetic Services Monitoring Group to take this work forward to publication.

For more information on this Monitoring Group visit the HGC's website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=253>

Genetic Services Monitoring Group

The Genetic Services Group was placed on hold in 2003 while it transferred its attention to the Commission's substantive piece of work on the ethical and scientific aspects of profiling babies at birth. This work finished at the end of March 2005 when the Commission published *Profiling the newborn: a prospective gene technology?* Following the completion of this work the group re-formed and met in September 2005.

At the first meeting the group updated their terms of reference to remove the reference to the group visiting NHS laboratories. They also highlighted their priorities for future work.

At the February plenary meeting the genetic services subgroup agreed to take on responsibility for issues relating to paternity as the workload of the Identity Testing Monitoring Group was high.

Over the coming reporting year, the Genetic Services Group will be:

- following up HGC's report *Genes Direct: Ensuring the effective oversight of genetic tests supplied directly to the public*;
- inputting into the Health Department's review of the Code of Practice on Paternity Testing;
- monitoring how current NHS reforms are impacting on genetic services, and
- taking an interest in the Discrimination Monitoring Groups work on the electronic patient record and national programme for IT.

For more information on this Monitoring Group visit the HGC's website:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=260>

Membership during the reporting period

Christine Patch (Lead)

Stephen Bain

Angus Clarke

Paul Darragh

Paul Debenham

Frances Flinter

Rosemary Leonard

Rosalind Skinner

Peter Sayers

Pritti Mehta (co-opted)

Prisca Middlemiss (co-opted)

Annex A: Membership

The Human Genetics Commission

Chair

Baroness Helena Kennedy

Barrister and broadcaster

Vice-Chair

Sir John Sulston

Former Director of the Wellcome Trust Sanger Institute, Hinxton, Cambridge

Members

Dr Bill Albert (until December 2005)

Co-director IDEA (International Disability Equality Agency)

Professor Brenda Almond

Professor of Moral & Social Philosophy
Hull University

Professor Stephen Bain

Professor of Medicine (Diabetes), Swansea NHS Trust

Dr Celia Brazell

Director of Science and Technology,
GlaxoSmithKline

Professor Sarah Cunningham-Burley (from January 2006)

Professor of Medical and Family Sociology and co-director at the Centre for Research on Families and Relationships, University of Edinburgh

Dr Paul Debenham

Director, Life Science, LGC Limited

Dr Frances Flinter (from January 2006)

Clinical Director and Consultant Clinical Geneticist, Genetics Centre, Genetics Department, Guy's and St Thomas' NHS Foundation Trust

Ms Ros Gardner (from January 2006)

Ms Gardner runs a consultancy specialising in customer care excellence and complaint handling

Professor John Harris

Sir David Alliance Professor of Bioethics,
University of Manchester

Mr Michael Harrison

Barrister

Dr Iona Heath

General Practitioner, London

Professor Christopher Higgins

(from January 2006)

Director of the MRC Clinical Sciences Centre and Professor and Head of Division of Clinical Sciences at Imperial College London

Dr Susan Johnson (Until September 2005)

Lecturer in Adult Health, School of Nursing,
University of Nottingham

Mr Alastair Kent

Director, Genetics Interest Group

Ms Suzi Leather (ex-officio)

Chair of Human Fertilisation and Embryology Authority

Dr Rosemary Leonard (from January 2006)

GP and resident GP on BBC1's Breakfast News

Ms Alice Maynard (from January 2006)

Managing Director of Future Inclusion

Ms Hilary Newiss (until December 2005)

Lawyer

Ms Lola Oni (from January 2006)

Professional Services Manager
Haemoglobinopathies, Brent Sickle Cell/
Thalassaemia Centre, NW London Hospitals
NHS Trust

Dr Christine Patch

Genetic Counsellor Manager, Guys and St Thomas' NHS Trust

Professor Martin Richards

(until December 2005)

Professor of Family Research, Centre for Family Research, University of Cambridge

Mr Peter Sayers

Former Chair of the Telecommunications Advisory Panel

Professor Veronica van Heyningen (until December 2005)

Head of Cell Genetics Section, MRC Human Genetics Unit, Edinburgh

Mr Geoff Watts (until December 2005)

Journalist and presenter of BBC Radio 4's Leading Edge

Representatives of the Chief Medical Officers

Each of the four UK Chief Medical Officers will be able to participate in HGC or nominate a representative with observer status.

Dr Paul Darragh (Northern Ireland)

Consultant, Public Health Medicine Eastern Health & Social Services Board

Professor Angus Clarke (Wales)

Honorary Consultant in Clinical Genetics, University of Wales College of Medicine

Dr Sheila Adam (England)

Director of public health with NHS London, the Strategic Health Authority for London.

Dr Rosalind Skinner (Scotland)

Principal Medical Officer of Public Health Medical Division, SEHD

Co-opted Members**Dr Heather Draper** (Co-opted Member,

Working Group on Reproductive Choice)

Senior Lecturer, Centre for Biomedical Ethics, University of Birmingham

Dr Pritti Mehta

(Co-opted Member, Genetic Services Group)

Equity and Access Programme Manager, Genetic Interest Group

Ms Prisca Middlemiss (Co-opted Member, Genetic Services Group)

Information Officer, Unique – Rare Chromosome Disorder Support Group

Professor Patrick Morrison (Discrimination Monitoring Group)

Consultant in Clinical Genetics, Belfast City Hospital Trust

Secretariat

Mrs Gwen Nightingale, Secretary

Miss Sarah Connelly

Mrs Margaret Straughan

Dr Sophie Taysom (until November 2005)

Miss Joanna Edwards (from November 2005)

Mr Pat Wilson (Press Officer)

Annex B: How HGC works (role, terms of reference, methods of working and code of practice)

Role

The Human Genetics Commission (HGC) is the UK Government's advisory body on how new developments in human genetics will impact on people and on health care. Its remit is to give Ministers strategic advice on the “big picture” of human genetics, with a particular focus on social and ethical issues.

The HGC was established in 1999 following the UK Government's comprehensive review of the regulatory and advisory framework for biotechnology. Its role should also be seen in the context of other advisory and regulatory bodies in the framework for human genetics. HGC does not direct these bodies or interfere with their lines of accountability, but works with them and helps form links between them. HGC reports to Health and Science Ministers and works within the context of devolution settlements for Scotland, Wales and Northern Ireland. Government policy on human genetics is generally developed on a UK basis, but responsibility for National Health Service (NHS) genetics services is the responsibility of each devolved administration.

Terms of Reference

- To analyse current and potential developments in human genetics and advise Ministers on:
 - their likely impact on human health and healthcare;
 - their social, ethical, legal and economic implications.
- To advise on strategic priorities in the delivery of genetic services by the NHS.
- To advise on strategic priorities for research.
- To develop and implement a strategy to involve and consult the public and other stakeholders and encourage debate on the development and use of human genetic technologies and advise on ways of increasing public knowledge and understanding.
- To co-ordinate and exchange information with relevant bodies in order to:
 - identify and advise on the effectiveness of existing guidance and of the regulatory and advisory framework as a whole, taking account of European and global dimensions;
 - look at the lessons learnt from individual cases requiring regulatory decision to build up a wider picture.
- To consider specific issues related to human genetics and related technologies as requested by Ministers.
- To operate in accordance with best practice for public bodies with regard to openness, transparency, accessibility, timeliness and exchange of information.

Ways of working

A constant theme and priority within the Commission's work is to actively seek input from the public and other stakeholders and this involves a variety of consultation exercises and open meetings.

We work in accordance with best practice principles on openness and transparency. We also exchange information with other bodies in the advisory and regulatory framework, including meetings at secretariat level and between chairs.

We have established Monitoring Groups which involve both Members and external participants, and which may co-opt input from individuals. We use email and telephone conferencing when this is useful, particularly for the work of the Monitoring Groups described below.

The HGC may commission work from individuals or organisations on a consultancy basis.

How we organise our work

The full Commission meets around four times a year, in different parts of the country. We usually meet over two days, holding an information-gathering session, when we invite a number of people to talk to us about a particular issue, on one day and the plenary meeting on the other.

In 2003, we set up a more flexible structure for the way the Commission carries out its work. We agreed to continue to focus the main areas of work in task-orientated working groups. We also identified HGC Members to lead on a number of key issues and who work with Monitoring Groups to keep a watching brief on these areas and keep them high on our agenda. With the new membership intake in 2006, we reviewed these Monitoring Groups and made minor changes to their Terms of Reference.

Lead Members are asked to:

- keep HGC up to date on developments and make sure the issue remains on HGC's agenda
- advise on the need for meetings of the Monitoring Group and suggest specific pieces of work as needed
- lead on liaising with other relevant organisations and co-ordinating responses to consultations

The following Monitoring Groups operated in 2005/06:

- Genetic Discrimination Monitoring Group
- Horizon-Scanning Monitoring Group
- Intellectual Property and Genetics Monitoring Group
- Public Involvement Monitoring Group
- Database Monitoring Group
- Identity Testing Monitoring Group
- Genetic Services Monitoring Group

The work of the Monitoring Groups is described in the body of this report.

The **Business Committee** continued with its existing role (see bullet points below) and in February, took over formal responsibility for all HGC public involvement work.

The Committee:

- Provides a more responsive executive structure so that HGC can react to developments quickly and involve the Membership as fully as possible.
- Liaises with lead members between plenary meetings and with key organisations such as Nuffield, Wellcome
- Oversees external communications:
 - press office
 - website
 - newsletter/annual report
 - editorial oversight of briefing notes

Working Groups

The Commission decided that our Working Groups were very good models for taking forward large pieces of work and that we would continue to set up a specific group to deal with an individual area of work. This year we had one working group on **Genetics and Reproductive Decision Making** and have set up another group which will oversee the arrangements for the **HGC's Citizens' Jury in 2006**. More information on these work strands can be found in the main text.

Code of Practice for Members

The HGC Code of Practice was prepared in line with Government policy on standards in public life, openness and accountability, full details are available on the HGC website: www.hgc.gov.uk. The Chair, Vice-Chair, Members and Representatives of the Chief Medical Officers (collectively referred to as "Members") are expected to follow it in carrying out duties associated with HGC. Co-opted members are also expected to follow the Code as it applies to the work they do on behalf of HGC.

A copy of the Code of Practice can be found on the HGC website at:
<http://www.hgc.gov.uk/Client/Content.asp?ContentId=5>

Annex C: Register of members interests

(This register provides details in respect of all HGC members for the period April 2005 to April 2006)

Dr Sheila Adam

Remunerated employment, office, profession, etc

Director of public health with NHS London, the Strategic Health Authority for London

Miscellaneous and unremunerated interests

Honorary chair in public health with Queen Mary's University of London
Independent trustee of the Disasters Emergency Committee
Family member is a partner in Mitchell Damon

Dr Bill Albert

Remunerated employment, office, profession, etc

Co-director IDEA (International Disability Equality Agency)

Miscellaneous and unremunerated interests

Chair of Bioethics Committee Disabled People's International Europe, Member of International Committee of the British Council of Disabled People (IBCODP)

Professor Brenda Almond

Remunerated employment, office, profession, etc

Author, editor, lecturer (occasional, free-lance)

Miscellaneous and unremunerated interests

President of Philosophical Society of England
Vice-president of Society for Applied Philosophy
Overseas Member of Austrian Academy of Sciences
Member of Societas Ethica (European Society for Ethical Research) and of European Ethics Network

Professor Stephen Bain

Remunerated employment, office, profession, etc

Professor of Medicine (Diabetes), Swansea NHS Trust

Dr Bain has also received lecture fees from Aventis, Boehringer Ingelheim, Eli Lilly, GlaxoSmithKline, Merck Sharp Dome, Novartis, Novo Nordisk, Pfizer, Servier & Takeda and Solvay. He has been awarded research & clinical grants by Aventis, Eli Lilly, Novo Nordisk & Sequana Inc and has sat on advisory boards for Eli Lilly, Merck Sharp Dome and Novo Nordisk & Sequana Inc.

Miscellaneous and unremunerated interests

Former Member, West Midlands Multi Research Ethics Committee
Former Chairman of the Pan-Birmingham Diabetes Advisory Group and the East Birmingham and Solihull Local Diabetes Services Advisory Groups

Dr Celia Brazell

Remunerated employment, office, profession, etc

Director, Genetics Science and Technology, GlaxoSmithKline Research and Development

Registrable shareholdings

Aberdeen Technology Trust
The AIM Trust plc
Fidelity American Fund
Fidelity UK Aggressive Unit Trust
Fidelity Special Sit Trust (1) & (2)
GlaxoSmithKline
Invesco Perpetual: Far Eastern Growth
Schroders: Tokyo Fund

Miscellaneous and unremunerated interests

Member, Department of Health Advisory Group for Genetics Research
Chair of Pharmacogenetic Group – European Federation of Pharmaceutical Industry Association (EFPIA)
Member of Advisory Board of Cesagen

Professor Angus Clarke

Remunerated employment, office, profession, etc

Professor of Clinical Genetics, Department of Medical Genetics, Cardiff University
Salary sourced from NHS (60%) and HEFCW (40%)
Recipient of research funds from The Wellcome Trust, Rett Syndrome Association UK, Jeans 4 Genes and the ESRC
Author and editor of several books

Miscellaneous and unremunerated interests:

Fellowships of Royal Colleges of (1) Physicians of London and (2) Paediatrics and Child Health
Membership of: British Medical Association; NHS Consultants' Association; Clinical Genetics Society; British Society of Human Genetics; European Society of Human Genetics; European Society for the Philosophy of Medicine and Health Care
Chair, Medical Advisory Board, Ectodermal Dysplasia Society
Medical Advisor, Rett Syndrome Association UK and Rett Syndrome Association Scotland.
Member, Editorial Boards of: Communication and Medicine, Genomic Medicine.
Supporter of Greenpeace; Religious Society of Friends; Oxfam; Christian Aid; Amnesty International

Professor Sarah Cunningham-Burley
Remunerated employment, office, profession etc

Professor of Medical and Family Sociology, Division of Community Health Sciences (Public Health Sciences) and Co-Director, Centre for Research on Families and Relationships, University of Edinburgh
Salary sourced from Scottish Higher Education Funding Council
Recipient of research funds from the Economic and Social Research Council and Scottish Executive, Office of the Chief Researcher and Education Department; previously also Joseph Rowntree Foundation, Health Scotland, Chief Scientist Office (Scottish Executive)
Occasional remuneration in connection with professional services (eg. examining, publications, research consultancies)

Miscellaneous and unremunerated interests

Member of Scientific Committee for Generation Scotland
Member of the British Sociological Association
Member of the Society for Social Medicine
Trustee, Edinburgh Rudolf Steiner School
Signatory, Charter 88

Dr Paul Darragh

Remunerated employment, office, profession, etc

Consultant in Public Health Medicine, Eastern Health and Social Services Board
Non-Executive Member of the Health Protection Agency Board

Miscellaneous and unremunerated interests

Director of Townsend Enterprize Park – training and workspace letting
Chairman of Townsend Social Outreach Centre – Community development, youth work
Dun's Librarian – Royal College of Physicians (RCPI), Ireland
Member, Council RCPI

Dr Paul Debenham**Remunerated employment, office, profession, etc**

Director, Life Sciences, LGC Limited.

Registrable shareholdings

Astra Zeneca
Syngenta

Dr Frances Flinter**Remunerated employment, office, profession, etc**

Senior Lecturer/Honorary Consultant in Clinical Genetics, King's College London (NHS funded)

New title with effect from April 2006:
Consultant Clinical Geneticist and Clinical Director of Children's Services and Genetics

Mrs Ros Gardner**Remunerated employment, office, profession etc**

Managing Director of Ros Gardner Associates Limited

Member of the School Teachers Review Body
Council member of the Nursing and Midwifery Council

Independent Complaints Mediator of the Criminal Records Bureau
Deputy Independent Complaints Examiner for the Dispute Service

Miscellaneous and unremunerated interests

Trustee of Alcohol Services to the Community
Lay Assessor, NHS Appointments Commission
Member of the British & Irish Ombudsmen's Association
Adviser Thames Water Customer Assistance Panel
Founder Director of the Professional Speakers Association
Member National Consumer Group
Member, Vice President and President of the Society of Consumer Affairs Professionals

Professor John Harris**Remunerated employment, office, profession, etc**

Sir David Alliance Professor of Bioethics, University of Manchester

Visiting Professor of Philosophy, London School of Economics and Political Science
His research is currently supported by The European Commission, The British Embassy, Washington and The Greenwall Foundation

Mr Michael Harrison**Remunerated employment, office, profession etc**

Barrister, London

Miscellaneous and unremunerated interests

Member, Gene Therapy Advisory Committee

Dr Iona Heath**Remunerated employment, office, profession etc**

General Practitioner, Kentish Town, London

Miscellaneous and unremunerated interests

Nationally elected member of the council of the Royal College of General Practitioners
Chair of the Ethics Committee of the British Medical Journal
Member of Medact and British Medical Association
Supporter of Oxfam, Amnesty International, Friends of the Earth, Medical Foundation for the Victims of Torture, Centre for Young Musicians, Little Sparta Trust

Professor Christopher Higgins**Remunerated employment, office, profession etc**

Director, Medical Research Council, UK
Head of Division, Imperial College London

Remunerated directorships

Chair – Scientific Advisory Board, Microscience

Miscellaneous and unremunerated interests

Chair Spongiform Encephalopathy Advisory Committee
Executive Council, Association of Medical Research Charities

Mrs Susan Johnson

Remunerated employment, office, profession, etc

Lecturer, School of Nursing, University of Nottingham
Research Fellow, Institute for the Study of Genetics, Biorisks and Society, University of Nottingham
Staff Nurse, United Lincolnshire Hospitals NHS Trust

Baroness Helena Kennedy QC

Remunerated employment, office, profession, etc

Board Member
Independent Newspapers
Member of the Bar

Miscellaneous and unremunerated interests

Advisory Council Member of the Foreign Policy Centre
Bencher of Gray's Inn Chambers
Board Member, British Museum
Board Member, Tablet Trust
Chair of Arts and Business
Chair of the Board of Governors, Atlantic College
Chair of Power Inquiry
Chair of Standing Committee for Youth Justice
Fellow of the Royal Society of Arts
Fellow of the City and Guilds Institute
Fellow of the Institute of Advanced Legal Studies
Member of Academie Universalle des Cultures
Member of Foreign Policy Centre Advisory Council
Member of the External Advisory Council, World Bank Institute
Patron, Charter 88
Patron, Liberty
Patron, Howard League Reform

Patron, Poets and the City
President, Civil Liberties Trust
President of The School of Oriental and African Studies
Trustee, KPMG Charitable Trust
Trustee, Media Standards Trust
Vice-President, Association of Woman Barristers
Vice-President, Haldane Society

Political activity

Labour Peer

Mr Alastair Kent

Remunerated employment, office, profession, etc

Director, Genetic Interest Group
Non-Executive Director, Cambridge City Primary City Trust
Member, Health Equality Europe

Miscellaneous & unremunerated interests

Member, Joint Committee on Medical Genetics
Member, Association of British Insurers (ABI) Genetics Committee
Member, Genetic Commissioning Advisory Group (DH)
Member, Genetics Commissioning Group (London NHS)
Member, Orphan Medicinal Products Committee (EMA) (until April 2006)
Member, Progress Educational Trust Advisory Committee
Justice of the Peace, Cambridge (until February 2006)

Ms Suzi Leather

Remunerated employment, office, profession, etc

Chair, Human Embryology and Fertilisation Authority

Miscellaneous and unremunerated interests

Member, Christian Socialist Movement
Individual Member, National Heart Forum
Member, Child Poverty Action Group
Member, Organophosphate Information Network

Member of Council, University of Exeter
 Member of the Chancellor's Advisory Council,
 University of Exeter
 Glasgow Centre for Population Health –
 Member of the External Advisory Group
 Member of the Better Hospital Food Forum
 Chair of Steering Committee (Tommy's the
 Baby Charity) – Teenage Pregnancies: Dietary
 Measures to improve nutrition and pregnancy
 outcome
 Fellow [ad eundem], Royal College of
 Obstetricians and Gynaecologists
 Member of the International Advisory Board
 of the 6th EU Framework Programme for
 Research and Technology Participatory,
 Governance and Institutional Innovation
 Project (PAGANINI), University of Vienna

Political activity

Labour Party Member

Dr Rosemary Leonard, MBE

Remunerated employment, office, profession, etc

NHS General Practitioner
 Paid Retainer Express Newspapers and the
 BBC
 Regular contributor to Woman and Home
 magazine (IPC magazines) and the Tesco
 Healthy Living Club magazine

Ms Alice Maynard

Remunerated employment, office, profession, etc

Managing Director of Future Inclusion Ltd.
 Member of the Eastern Region Committee of
 Jephson Housing Association

Miscellaneous and unremunerated interests

Company Secretary, Equal Ability CIC
 Associate of the Employers' Forum on
 Disability
 Executive Committee Member of Milton
 Keynes Racial Equality Council
 Member of the British Council of Disabled
 People
 Member of Greater London Action on
 Disability

Member of Milton Keynes Centre for
 Integrated Living
 Advisory Group Member, JMU Access
 Partnership
 Advisory Group Member, Milton Keynes
 Common Purpose
 Supporter of Friends of the Earth, Amnesty
 International, ActionAid, Shelter, WaterAid,
 NSPCC and Ethopiaid

Ms Hilary Newiss

Remunerated employment, office, profession etc

Lawyer, formerly partner Denton Hall
 solicitors

Registrable shareholdings

GlaxoSmithKline

Miscellaneous and unremunerated interests

Member, BioIndustry Association (BIA)
 Member, Intellectual Property Advisory
 Committee of DTI
 Member, External Ethical Advisory Board,
 Pharmagene Limited

Ms Lola Oni

Remunerated employment, office, profession etc

Professional Services Manager
 Haemoglobinopathies, Brent Sickle Cell/
 Thalassaemia Centre, NW London Hospitals
 NHS Trust

Miscellaneous and unremunerated interests

Member of Nigerian Leadership Initiative
 Member of NHS Sickle Cell and Thalassaemia
 National Steering Group
 Secretary to the First Martin Luther King
 Twelve
 Trustee of the Martin Luther King Memorial
 Trust

Dr Christine Patch**Remunerated employment, office, profession, etc**

Genetic Counsellor Manager Clinical Genetics
Department Guys and St Thomas' NHS
Foundation Trust

Miscellaneous and unremunerated interests

Visiting Fellow Public Health Sciences and
Medical Statistics University of Southampton
Member of the UK Genetic Testing Network
Member of the Professional and Public Policy
Committee of the European Society for
Human Genetics
Co-chair of the Ethics and Public Policy
Committee of the International Society of
Nurses in Genetics

Professor Martin Richards**Remunerated employment, office, profession, etc**

Professor of Family Research, Centre for
Family Research, University of Cambridge
Grants, Wellcome Foundation
Previous grants, Medical Research Council and
Cancer Research Campaign
Member, Wellcome Trust Biomedical Ethics
Panel

Registrable shareholdings

CGNU Ordinary CBPO. 25 shares (formerly
Norwich Union)

Miscellaneous and unremunerated interests

Member, Friends of the Earth
Member, North Cumbria Community Genetics
Project Ethics Committee
Member, Human Fertilisation and Embryology
Authority, Ethics and Law Committee
Member of Advisory Boards of the Cambridge
Genetic Knowledge Park and Cesagen
Adviser to Genetics Interest Group

Political activity

Member of the Labour Party

Mr Peter Sayers**Remunerated employment, office, profession, etc**

Director, IDM Ltd (Internet Design company)
Non-Executive Director NHS Cheltenham and
Tewkesbury Primary Care Trust
Chair of the PCT Audit Committee

Miscellaneous and unremunerated interests

Director, New Harmony Press (non-profit
publishing co-operative)
Director, Accessible Globe International Ltd
(non-trading disability travel company)
Company Secretary, Salt Marketing Ltd
(without remuneration)

Dr Rosalind Skinner**Remunerated employment, office, profession, etc**

Principal Medical Officer in the Scottish
Executive Health Department

Miscellaneous and unremunerated interests

Former clinical geneticist in the University
of Edinburgh

Sir John Sulston**Remunerated employment, office, profession, etc**

None, except for occasional freelance
payments

Miscellaneous and unremunerated interests

Supporter of Oxfam, Amnesty, Greenpeace

Professor Veronica van Heyningen**Remunerated employment, office, profession, etc**

Head of Cell Genetics Section, Medical
Research Council, Human Genetics Unit,
Edinburgh

Registrable shareholdings

GlaxoSmithKline
 Unilever
 Bernard Matthews (family)
 Boots (family)
 Diageo (family)
 Elan Corp (family)
 ICI (family)
 J Sainsbury (family)
 Nycomed Amersham (family)
 PPL Pharmaceuticals (family)
 Zeneca (family)

Mr Geoff Watts**Remunerated employment, office, profession, etc**

Journalism (writing and broadcasting), often requiring the collection of information on, the description of and the expression of opinions about topics in biology and medicine lying within the Commission's remit.

Occasionally chairs meetings and conferences, participant in recorded discussions and occasional paid consultant to organisations which may have an academic or commercial interest in some of the topics considered by the Commission. (No regular or continuing commitments of this kind.)

Register of Co-opted Members' Interests**Dr Heather Draper****Remunerated employment, office, profession, etc**

Senior Lecturer, Centre for Biomedical Ethics, University of Birmingham
 Occasionally paid for lectures on different aspects of medical ethics by eg hospitals, institutes of higher education and professional bodies such as the Association of Anaesthetists

Miscellaneous and unremunerated interests

Member, Advisory Committee on Ethics for the Assisted Conception Unit, Birmingham Women's Hospital
 Member, Clinical Ethics Committee for Heartlands and Solihull Hospitals Trust
 Member, Ethics Advisory Group for Birmingham Children's Hospital

Prisca Middlemiss**Remunerated employment, office, profession, etc**

Information Officer, Unique – Rare Chromosome Disorder Support Group
 Journalist, General Practitioner newspaper, Haymarket Medical Publications Ltd

Registrable shareholdings

Nestor Healthcare
 Pfizer

Dr Pritti Mehta**Remunerated employment office, profession, etc**

Equity and Access Programme Manager, Genetic Interest Group

Miscellaneous and unremunerated interests

Member, UK Genetic Testing Network (UKGTN) Gene Dossier and Directory Working Group
 Member, NHS and Sickle Cell & Thalassaemia Screening Programme Information for Users and Professionals Subgroup

Professor Patrick Morrison**Remunerated employment, office, profession, etc**

Consultant in Clinical Genetics, Belfast City Hospital Trust (fully funded by National Health Service)
 Postgraduate Tutor and Director of the Belfast Postgraduate Centre (funded by Northern Ireland Council for Postgraduate Medical and Dental Education)

Miscellaneous and unremunerated interests

Director of Cancer Genetics, Northern Ireland Regional Genetics Service
 Member, Northern Ireland Ethics Forum

Annex D: Finance

The Human Genetics Commission is funded by the Department of Health, Office of Science and Innovation and devolved administrations.

The majority of the HGC's operation budget (running costs) was spent on working in an open manner and public engagement work, with roughly:

- £135,000 spent on plenary meetings, monitoring groups, working groups and information gathering sessions and the Consultative Panel;
- £30,000 spent on external communications, including the press office, the PR function and website;
- £15,000 spent on publications, and
- £10,000 on the National Ethics Committee Event.

HGC also received additional funds for the recruitment process for 7 new members.

Fees are payable to Members at a rate of £148.59 per meeting, £180.40 per meeting for the Chair, and members are reimbursed for all reasonable travelling expenses.

Annex E: Published responses and memoranda

Summary of Consultative Panel feedback on the reproductive choice principles and recommendations – taken from discussion at Consultative Panel event held on 21st September 2005.

These summarised comments have been taken from a full transcript of the Consultative Panel discussion, which took place on Wednesday 21st September. The Panel were asked to base their response around three set discussion questions. Not all responses were structured in this way. What follows is a summary of the Panels' comments, which has been re-structured to relate to each of the three questions.

Question 1

Do the recommendations in the draft seem appropriate to you?

- Several tables of Members fed back that they found the recommendations to be unclear and had to ask HGC Members on the table what the Working Group had meant by them. There was a feeling that some of the language and terminology needed to be more clearly defined, for example, Members were not sure what the HGC meant by the terms 'genetic solidarity' and 'social responsibility'. If these terms were defined elsewhere in the report, they must be cross-referenced to aid reading.
- There was broad support for the principles and recommendations but some Members felt that the report did not address the practical problems that most providers would face when implementing them. It was felt that the report was describing the ideal state of affairs rather than the reality of NHS genetic services provision.

Panel Members also provided feedback on specific recommendations:

- There was strong support for the recommendation that the progress of children born following IVF or an embryo biopsy should be systematically followed-up. However, Members felt that the recommendation should also say that all follow up records should be anonymised. Further, they felt that the recommendation should go on to say that the Government must ensure funding for this work, so that it could be undertaken consistently over time and nationwide.
- One table commented that they found the recommendation on reproductive tourism unclear and that the report should be much more forceful in warning people about the differences and sometimes the inadequacies of screening systems abroad. They also felt that a distinction should be made between people who sought treatment abroad because it was not available here or was too expensive and those who sought a treatment because that particular service was not permitted here.
- One table felt that recommendation 4 should be more explicit and clearly state that couples should have the option of pre-natal screening, even if they had decided not to terminate.
- The same table felt that recommendation 9 could be tied to DH work relating to the Children Act, which is about ensuring provision so that every child with special needs has a named professional overseeing all aspects of care, including health, social services and education. Similarly, recommendation 20 could be cross-referenced to the new NICE guidelines on fertility treatment.
- One table thought that recommendation 33 could be placed earlier in the list as it was a broad statement about the priority that genetic screening should be given during pre-natal healthcare, set against maternal health, nutrition, etc.

- Finally, one table gave their strong support to recommendation 7, which related to carrier testing in children. The table agreed with the recommendation that testing for late onset conditions in children was not desirable.

Question 2

Are there any recommendations that you felt were missing?

There were two key issues on which every table made suggestions about how the content or approach of the report could be improved. They were the notion of choice and the provision of counselling.

- The consensus view amongst the group seemed to be that, if real choice was to be available when making decisions relating to reproductive choice, and there already was to a certain degree, then choice should be open to all and supported by information as well as counselling. One table commented that a supported choice was not just about receiving counselling, it was about practical support throughout the child's life. It was also about support in adulthood from the top down, this meant legislating so that people affected by a genetic disorder were not discriminated against in any way.
- Whilst there was general agreement that counselling should be available pre-conception and in early pregnancy, many Members felt that the report should be more robust in its view that parents had the right to opt out of the screening process. These Members felt that opting out of screening, or of reproduction altogether, was a legitimate and managed choice. It was suggested that a recommendation could be included which identified opting out as a real choice and one that should be supported by counselling. One Member also felt that the report should make reference to the fact that, in reality, having a choice was dependent on the stage of pregnancy at which the screening was undertaken.
- On the issue of counselling, a wide range of views were noted. Several Members felt that the report did not achieve the right balance on counselling. They argued that often there is too much counselling and there was some concern about whether some staff conducting this extra counselling were sufficiently qualified. Some Members felt that the requirements for informed consent in some cases was already excessive.
- One final point made by some Panel Members was that the report should be much clearer about what was and what was not within its remit. It should explicitly state that the report will not look at issues around sex selection, abortion or the legal status of the fetus.

Question 3

Does the text have the right tone? Is it easy to understand?

- A general point made by several tables was the need to cross-reference statements made in the recommendations (and the future executive summary) with the relevant background text/chapter in the body of the report in order to give the recommendations context. It should be clear that the recommendations follow from the wider discussions in the document.
- Some Panel Members felt that, the report erred on the side of political correctness and had a liberal tone and feel. They broadly agreed with this approach. However, a few tables made the point that they felt the desire not to offend in the report, led to some ambiguities in the content.
- One table felt strongly that the report should contain a paragraph noting the difference in views of those who view impairment as a good thing and those who do not. Ideally, the report would take a stance on this and point out the tremendous value of diversity in society. Use of language

was key and one table fed-back that phrases such as 'rectification of impairment' should be avoided in the report.

- Several tables also commented that the report did not make the point that screening can create a false sense of security in parents as it led them to believe that a physician can guarantee a healthy baby.
- The most negative comment regarding tone was that the report was clumsily written and that the language moved away from plain English in parts. Several Panel Members made the point that it was not at all clear to them to whom the report was aimed. Who was the key audience – professionals working in the field, the Government or the wider public?

Feedback on the issue of genetic discrimination

Question 1

What specific areas around genetic discrimination do you think the HGC should look at?

- There was widespread agreement that the HGC should look at discrimination in relation to all types of insurance. Some Panel members commented that they would wish to see an extension to the date of the insurance moratorium.
- Several tables raised the potential dangers around genetic testing in the workplace and stressed the need for protection against unfair discrimination in the workplace. Several tables commented that they were aware that discrimination in some work settings was necessary as, often, public safety was a factor, eg sight or heart complaints for pilots. However, the issue was to ensure that any discrimination was fair and balanced, and not solely based on the financial concerns of the employer.
- One table suggested that, when looking at discrimination, the Commission should start with screening at birth. They were particularly concerned that identification of specific conditions could lead to discrimination of different kinds, for example, they were aware that some Down's Syndrome patients and patients with heart abnormalities had been refused treatment on resource grounds, ie the treatment was too expensive to be administered on the NHS.

Question 2

Do you have any personal concerns in this area?

Three specific areas of concern mentioned were:

- Travel insurance – One Panel member commented that travel insurance was generally very cheap until they declared that they had a medical condition. They were then no longer eligible for budget deals.
- Insurance for self-employed people with a genetic illness.
- Pension schemes and discrimination on grounds of susceptibility to genetic illness.

Feedback on future work for the HGC

Question 1

Are there any specific issues that you would like the HGC to look at in the future?

Five topics were mentioned:

- Wider genetic susceptibility to illness, ie not only single gene disorders. It was felt that the HGC could look at this more closely as part of its work with the insurance industry.
- The National DNA Database. Several tables commented that they would like to know more about legal and ethical implications of the database.
- Equity as regards provision in private health care and the NHS.
- Education. Several Panel members felt that the HGC should take more of a role in educating the public about genetics. They felt that, on the whole, the public were quite ignorant about genetics and genetic illness and that the Commission could do a lot more to inform them.
- Review of public spending on genetics research. One table felt that the HGC should conduct a spending review of public spending in relation to genetic research, in order to assess whether the NHS was undertaking the appropriate level of research, or whether more public money should be spent in this area.

Question 2

What do you think about the Commission's work to date?

The general response to this question was that overall Panel members found the Commission's work to be very worthwhile. Several members said that they were not always clear on the outcomes to certain debates where the HGC had had some involvement. They felt that, unless they read the plenary minutes on the website, they were not able to keep abreast of new issues of concern or progress on work already underway.

There was strong approval of the HGC's work on confidentiality and the storage of genetic information but there was some confusion about the remit of the HGC. One table suggested that the HGC should have two separate roles, one of educating the public and the other to influence government. The same table felt that the HGC could be more of a resource for people with genetic disorders, for example, the HGC website could have a section, which listed patient groups and clinicians.

Human Genetics Commission written submission regarding the DNA amendment to the Police, Public Order and Criminal Justice (Scotland) Bill lodged by Paul Martin MSP

I would like to begin by saying that Members of the Human Genetics Commission (HGC) are grateful for the opportunity to comment on the draft amendment to the Police, Public Order and Criminal Justice (Scotland) Bill lodged by Paul Martin MSP, which would allow for the retention of DNA on police databases where a case does not result in a conviction.

The HGC is the Government's advisory body on current and potential developments in human genetics and the likely impact on human health and healthcare as well as the social, ethical, legal and economic implications. In considering national issues, the HGC adopts a UK perspective which includes taking account of legal and other differences between England, Scotland, Wales and Northern Ireland, and of the status of devolved and non-devolved matters. Our membership reflects UK-wide status and we also have Chief Medical Officer Representatives from England, Scotland, Wales and Northern Ireland sitting on the Commission.

The HGC set out its position in relation to the retention of samples where there is no conviction in August 2005, in its response to the Scottish Executive's draft proposals on the collection and retention of DNA samples and fingerprints in Scotland. The first question of that consultation asked:

"Do you agree that the police should be able to retain prints and samples taken from those who are arrested or detained on suspicion of committing an offence punishable by imprisonment whether or not they are later convicted of that offence?"

In response to that question, we first made a distinction between the retention of DNA samples from the retention of DNA profiles. The HGC still holds the view set out in its report *'Inside Information'*, that there are differing privacy concerns between a DNA sample and a DNA profile. A profile contains no relevant medical or predictive genetic data. However, the stored DNA sample has the potential to be used for further, more intrusive, testing for purposes of identification, or for predictive profiling for physical, behavioural or racial characteristics. The HGC wishes to see a further discussion of the justification of the retention of samples, particularly for those not convicted of an offence. The Commission's general view is that an assumption should be made that samples from those who are arrested and not charged or convicted should be destroyed when a successful profile has been obtained. Any proposal to routinely store such samples should be fully justified with regards to cost/benefit and to the legal and human rights concerns. If such storage is deemed to be essential, there may need to be additional safeguards to ensure that they are not used for other purposes without proper lawful reasons.

As I understand it, Mr Martin has tabled this amendment because he would like to bring Scottish legislation in this area in line with England and Wales. I would like to repeat the general point we made in August last year, in respect of key principles regarding the collection and retention of personal genetic information for forensic use. That is that we too would like the law in England and Wales and the law in Scotland to be identical so that those providing forensic services are clear about their duties in respect of retention. However, our preference would be that the unification be achieved the other way around, that is, by changing the law in England and Wales on this issue to bring it in-line with Scotland's position. In our response to the Scottish Executive's consultation, I gave the example of our support of the Scottish Executive's intention to keep the existing law relating to the collection and retention of fingerprints and samples provided voluntarily. In particular, we supported the caveat that consent to use samples and fingerprints provided voluntarily can be

withdrawn at any time. Ideally, we would like the law in England and Wales to be changed so that it reflected Scottish law, not vice versa.

I enclose a copy of the HGC's response to the Scottish Executive's draft proposals on the collection and retention of DNA samples and fingerprints in Scotland for your interest.

I hope you find these comments useful. I would appreciate if you could let me know the findings of your Committee on this matter.

Yours sincerely,
Professor Stephen Bain
Chair, Identity Testing Monitoring Group
Human Genetics Commission

Response to Scottish Executive Consultation on the collection and retention of DNA samples and fingerprints in Scotland

I would like to begin by saying that Members of the Human Genetics Commission (HGC) were grateful for the opportunity to comment on the Scottish Executive's draft proposals on the collection and retention of DNA samples and fingerprints in Scotland. As Chair of the HGC's Identity Testing Monitoring Group, I have been asked to respond to the consultation on behalf of my fellow Commissioners.

The HGC strongly supports the work of the police and the existence of the National DNA database as a criminal intelligence tool. However, the Commission is of the view that robust safeguards must be in place to ensure that the collection, retention and police use of samples does not discriminate against Scottish citizens.

The HGC position in respect of the forensic use of personal genetic information is set out in our report *'Inside Information – Balancing interests in the use of personal genetic data'* (May 2002). This report contains several recommendations to Government concerning appropriate ethical oversight of the National DNA Database and I enclose a copy for your interest.

You will see from the report that the HGC has long expounded the view that any proposals to change the law relating to the use of personal genetic information for forensic purposes should be subject to a full public debate in order to examine the ethical, consent and confidentiality issues. The Scottish public should be fully aware of any proposed legislative changes in this area.

My final general point before turning to the set questions is that, in respect of key principles regarding the collection and retention of personal genetic information for forensic use, the HGC would like the law in England and Wales and the law in Scotland to be identical so that those providing forensic services are clear about their duties in respect of retention. For example, as we make clear in our response to question 2 of this consultation, we support the Scottish Executive's intention to keep the existing law relating to the collection and retention of finger prints and samples provided voluntarily. In particular, we support the caveat that consent to use samples and fingerprints provided voluntarily can be withdrawn at any time. Ideally, the Commission would welcome a change in the law in England and Wales on this issue to bring it in-line with Scotland's position.

Our thoughts on the three consultation questions follow.

Question 1: Do you agree that the police should be able to retain prints and samples taken from those who are arrested or detained on suspicion of committing an offence punishable by imprisonment whether or not they are later convicted of that offence?

In order to respond to this question, the HGC would first wish to make a distinction between the retention of DNA samples from the retention of DNA profiles.

The HGC still holds the view set out in their report *'Inside Information'*, that there are differing privacy concerns between a DNA sample and a DNA profile. A profile contains no relevant medical or predictive genetic data. However, the stored DNA sample has the potential to be used for further, more intrusive, testing for purposes of identification, or for predictive profiling for physical, behavioural or racial characteristics. The HGC wishes to see a further discussion of the justification of the retention of samples, particularly for those not convicted of an offence. The Commission's general view is that an assumption should be made that samples from those who are arrested and not charged or convicted should be destroyed when a successful profile has been obtained. Any proposal to routinely store

such samples should be fully justified with regards to cost/benefit and to the legal and human rights concerns. If such storage is deemed to be essential, there may need to be additional safeguards to ensure that they are not used for other purposes without proper lawful reasons.

Question 2: Do you agree that samples given voluntarily should not be retained or checked against prints and samples taken from any crime scene without written consent and that the consent can be withdrawn in writing at any time?

The HGC strongly support the Scottish Executive's intention to keep the existing law relating to the collection and retention of finger prints and samples provided voluntarily. In particular, the HGC supports the caveat that consent to use samples and fingerprints provided voluntarily can be withdrawn at any time.

Question 3: Do you agree that the legislation should state that prints and samples retained by the police should only be used for purposes related to the prevention or detection of crime, the investigation of an offence or the conduct of a prosecution?

The HGC welcome the Scottish Executive's proposal to include a safeguard in the new Bill by requiring that all prints and samples retained by the police may only be used for purposes related to the prevention or detection of crime, the investigation of an offence or the conduct of a prosecution. The HGC views this proposal as vital, not only because it serves to safeguard individual liberties, but also because it ensures a level of public confidence in the database.

The Commission recognises that retained fingerprints and samples may be used for research and development purposes aimed at improving the detection and prevention of criminal activity. In the Commission's view, it is conceivable that some research projects could prove valuable to this aim. However, it is essential that appropriate safeguards are in place to oversee the use of samples for this purpose. The establishment of an independent research ethics committee to approve such research would be an important measure in ensuring that samples were used appropriately and would serve to maintain public confidence in police use of personal genetic information.

We are aware that there are ongoing discussions in England and Wales concerning an amendment to the Criminal Justice Act 2004, which would allow the police to also use samples when searching for missing persons. The HGC broadly supports this proposal and responded to that effect as part of the Home Office consultation, *'Consultation on Policing: Modernising police powers'* in November last year. A copy of that response is enclosed for your interest.

Whilst the circumstances leading to a person being missing may be related to a criminal offence, there might not necessarily be a criminal aspect to a person's disappearance. We would then raise this as a possible reason for the police to speculatively search retained fingerprints or samples in future, which would fall outside your definition of *"purposes related to the prevention or detection of crime, the investigation of an offence or the conduct of a prosecution."*

I hope you find these comments useful. We would appreciate being kept up to date on the progress of the consultation and the Police Bill.

Yours sincerely,
Professor Stephen Bain
Chair, Identity Testing Monitoring Group
Human Genetics Commission

Mr Alan Brown
Police Leadership and Power Unit
2nd Floor, Allington Towers
19 Arlington Street
London
SW1E 5EB

26 November 2004

Dear Alan,

Re: Consultation on Policing: Modernising police powers

Thank you for the opportunity to comment on the above document. I am replying on behalf of the Human Genetics Commission (HGC), an independent advisory body established to advise the UK Government on developments in human genetics, particularly their ethical, legal and social implications. We welcome your public consultation on plans to review police powers in order to meet community needs. Our comments on this consultation are focused on Chapter 6: Identification; and reflect discussions held at HGC's September plenary meeting, and by the Commission's Identity Testing Monitoring Group.

With regard to the use of speculative searches of the National DNA Database (paras. 6.14-6.15), HGC is broadly content with the development of a Missing Person's DNA Database and the notion that police would need a separate authority to speculatively search these profiles against the National DNA database subject sample record and other profiles held by, or on behalf of, the police for identification purposes. There are however two caveats to this.

The first is that HGC would like some clarification on how the separate authority would operate and whether or not it would be led by the ACPO Chair of the National DNA Database Board.

The second relates to the Missing Person's DNA database and the questions around taking samples from a missing person's genetic relatives. We would be concerned by there being any legal obligation for missing person's genetic relatives to provide samples. The emphasis should be on requesting information and we would appreciate some clarification on this matter. In addition, as you may be aware, an area of interest to HGC is relationship testing, and the capacity of such testing to potentially reveal non-paternity. We feel that due consideration must be given to weighing up the value of the genetic information (i.e. identification of missing person) against the harm that the revelation of inadvertent information may do (eg. revelation of non-paternity). We would suggest though that on balance, however, and with the suitable emphasis on the proper use of DNA testing, any possible harm would be outweighed by the potential benefit of such testing.

The final point we would like to make refers to the taking of DNA samples covertly (para. 6.19). In our report, *Inside Information: Balancing interests in the use of personal genetic data*, (May 2002: copy enclosed), we recommended that consideration be given to the creation of a criminal offence of the non-consensual or deceitful obtaining and/or analysis of personal genetic information for non-medical purposes (Chapter 3). This recommendation has now been taken on board in the new *Human Tissue Act (2004)*. While we understand that such a law should not interfere unduly with police powers, we would like to seek some assurances of the circumstances under which such samples would be taken and clarification on what happens to samples after the completion of such

an investigation. Finally, we believe that such circumstances would need to be governed via a tight set of regulatory and/or legislative controls.

We would appreciate being kept up to date on the progress of your work in this area.

Yours sincerely,
Dr Stephen Bain
Lead Member on Identity Testing
Human Genetics Commission

Response to the Human Tissue Authority's consultation on their draft Codes of Practice

Codes of Practice Consultation
Human Tissue Authority
Finlaison House
15-17 Furnival Street
London
EC4A 1AB

3rd October 2005

Dear Sir/Madam

Re: Codes of Practice Consultation

Thank you for inviting the Human Genetics Commission's views on the Human Tissue Authority's draft codes of practice. As Secretary to the Human Genetics Commission (HGC), I have been asked to reply on their behalf in respect of *Code of Practice 1: Consent*.

I should begin by saying that the code of practice on consent was included in the papers for the last HGC plenary meeting on the 20th of September as part of a wider discussion relating to paternity testing. I am aware that your consultation pack contains a questionnaire which lists a series of general and specific questions. Regrettably, Members' discussion around the merits of the code of practice on consent was rather general and it has not been possible to structure their response in this way. I do apologise for any inconvenience this may cause.

The first important point to make is that Members were broadly content with the draft code on consent. The HGC has taken a close interest in the passage of the Human Tissue Act 2005 and have expressed views on how the overall protections should apply with respect to untraceable people, testing of material from the dead and the hierarchy of consent. The Commission is broadly content with the drafting of the code of practice on consent. Members would be happy to assist with any further detailed guidance on these points and would commend to you the guidance prepared by the Joint Committee on Medical Genetics, *Consent and confidentiality in genetic practice: guidance on genetic testing and sharing genetic information*, which will be published shortly.

As you will be aware, the Government's announcement in the Genetics White Paper that the Human Tissue Bill would introduce a new offence of testing an individual's DNA without their consent followed a Human Genetics Commission recommendation to change the law to prevent non-consensual genetic testing, including paternity testing. The Commission therefore welcomes section 45 of the Human Tissue Act 2005, which makes it an offence to have DNA for the purposes of analysing DNA without consent and is pleased that this change in the law is clearly set out in the draft code of practice.

The HGC remains concerned about the practices of some genetic testing companies which openly flout the voluntary UK Health Departments *Code of Practice and Guidance on Genetic Paternity Services* (March 2001). The HGC has been asked by the Department of Health for views on the revision of the code of practice and to consider how best to prevent testing companies from straying into practices that the section 45 non-consensual DNA testing offence is designed to prevent.

The *Code of Practice and Guidance on Genetic Paternity Services* will have to be reviewed before the Human Tissue Act comes into force in 2006. At the plenary meeting, HGC Members felt that as the new regulating body responsible for giving advice and guidance in relation to the Human Tissue Act as well as for some licensing establishments, consideration should be given to whether it would be appropriate for the Human Tissue Authority to regulate paternity testing services. They therefore thought it vital that the Human Tissue Authority should also be closely involved with the review in order to ensure greater awareness of and compliance with the revised code.

You may be interested to know that HGC plenary meetings are held in public and the minutes of the meeting, together with an audio file, are posted on the HGC website. If you would like to hear the full discussion relating to paternity testing, you can visit the website at www.hgc.gov.uk.

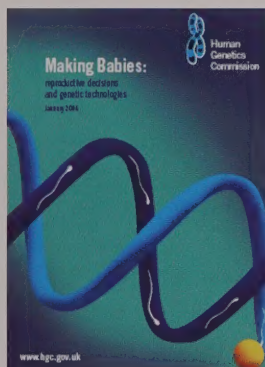
I do hope these comments are useful to you. Thank you again for approaching the Commission for their views.

Yours sincerely,
Sarah Connelly
Policy Manager, Human Genetics Commission Secretariat

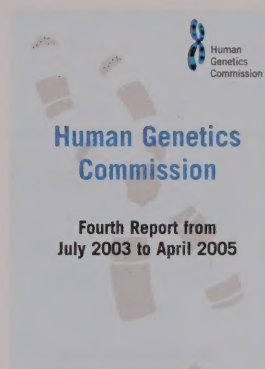
Annex F: Publications

The following publications are downloadable from the HGC website (hgc.gov.uk) and in hard copy from the addresses stated.

Reports and Publications

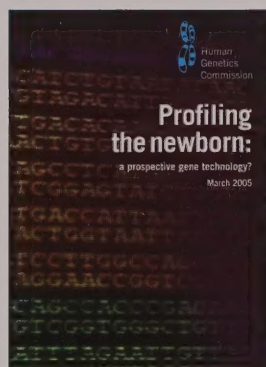


Making Babies:
reproductive decisions
and genetic technologies
Jan 2006 (ref 272321)*

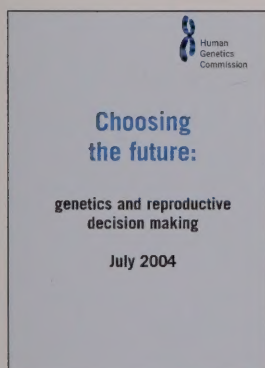
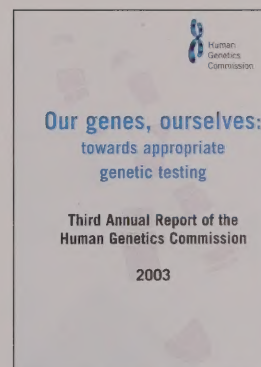


*Human Genetics
Commission*
Fourth Annual Report of
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Commission, 2005
(ref 269491)

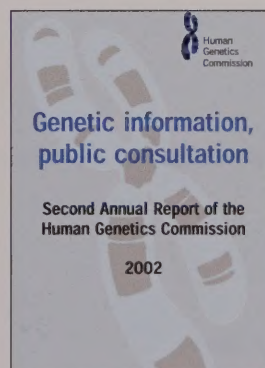
*Profiling the newborn:
a prospective gene
technology?*
March 2005 (ref 267377)*



*Our genes, ourselves:
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genetic testing.*
Third Annual Report of the
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2003 (ref 34587)



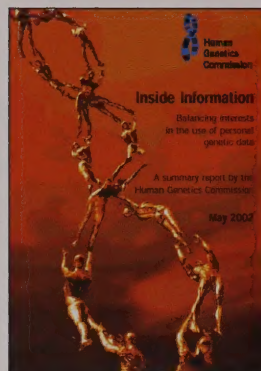
*Choosing the future:
genetics and reproductive
decision making*
July 2004 (ref 40293)



*Genetic information,
public consultation*
Second Annual Report of
the Human Genetics
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(ref 30449)

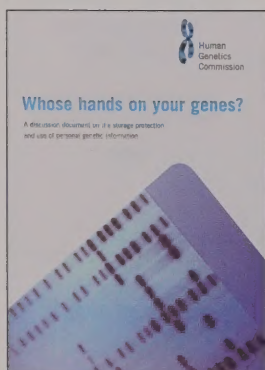
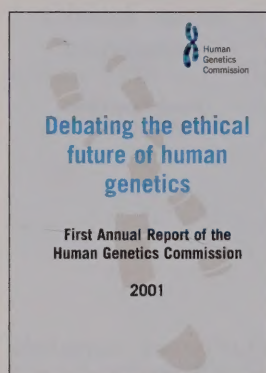


*Genes direct:
Ensuring the effective
oversight of genetic tests
supplied directly to the
public*
April 2003 (ref 31433)

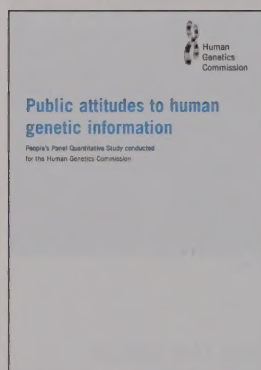


*Inside Information
Balancing interests in the
use of personal genetic
data May 2002
(ref 27907)**

*Debating the ethical
future of human genetics*
First Annual Report of
the Human Genetics
Commission
2001 (ref 25256)



*Whose hands on
your genes?*
November 2000
(ref 228048)



*Public attitudes to
human genetic
information,
March 2000 (ref 23992)*

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Keeping in touch

Tell us what you think

We are always keen to hear what you think and would welcome your comments about any aspect of our work.

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